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Life In Prostate Cancer Patients

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CONTRACTING ORGANIZATION: Johns Hopkins University
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FOREWORD

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Janice V. Bowie 11.3.99
PI - Signature Date

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INTRODUCTION

The goal of the training grant was to examine the influence of religion and spirituality on prostate cancer as a measure of quality of life (QOL). The specific aims addressed during the six month period included: (1) a review the literature on prostate cancer, QOL, religiosity and spirituality, and coping to gain an understanding of these relationships to cancer patients and treatment outcomes; (2) qualitative data collection using focus groups to elicit beliefs about religion and spirituality in the lives of prostate cancer patients; (3) a supplemental quantitative survey to further assess patients' perceptions of spirituality, knowledge of prostate cancer, diagnosis, treatment, social support and satisfaction with care received by their physician(s). It is intended that the data collected will lead to the development of a prostate-specific instrument to measure the role of spirituality as a domain of QOL and add to the base of knowledge on the use of spiritual resources as a potential means of coping with prostate cancer.

BODY

This section lists each task outlined in the approved Statement of Work and provides a detailed summary of each of the activities for the period of the training grant.

Task 1 Convene first meeting with collaborative investigator for project startup.

- a) A series of telephone conferences and e-mails occurred in lieu of a first meeting with the collaborative investigator, Dr. Kenneth Pargament. The content of these discussions focused primarily on the identification of appropriate literature and existing spirituality and quality of life instruments.
- b) The training grant proposal requirements and proposed time frame for accomplishment of tasks were reviewed with Dr. Pargament. He was given a copy of the proposal and project activities were also discussed during telephone conversations.
- c) Dr. Pargament identified and supplied a number of sources of literature and spirituality instruments which were reviewed for inclusion in a draft focus group guide and/or subsequent prostate spirituality instrument. A preliminary draft of the guide was developed and circulated to the study team. A telephone conference between the study team and Dr. Pargament took place and a faculty member, Dr. Barbara Curbow (Investigator on a related prostate cancer study headed by Dr. Bowie), provided consultation to this phase of the project. Dr. Curbow has extensive experience in cancer and quality of life research.
- d) Bruce Sanders was identified to fill the Research Assistant position. Mr. Sanders has several years of experience in directing projects and collecting data.

Task 2 Plan instrument development for focus groups.

- a) The literature and spirituality instruments previously mentioned were refined during this phase. The study team narrowed down the literature and included items in those instruments that were more likely to pertain to the focus of the study. A second draft of the focus group discussion guide was developed and shared with the study team in preparation for a meeting with the collaborative investigator.
- b) Logistical matters were finalized for Bruce Sanders to work in the capacity as research assistant/ project coordinator. Dr. Michal Granot would assist with the project as part of her postdoctoral training experience. However, no costs were associated with her involvement.
- c) Steps were initiated to identify participants for the focus groups. This process took place in several ways: (1) letters and telephone calls to urologists, oncologists, and support groups; (2) flyers, newspaper advertisements, and word of mouth, and (3) participation in a popular morning radio talk show. See **Attachment A** for copies of ads and flyers used for recruiting focus group participants.

The recruitment criteria included men between the ages of 50 and 75 who had been diagnosed with prostate cancer by a physician, spoke English, and could read and write. Persons interested or wanting more information about the focus groups were instructed to call Mr. Sanders, who screened the callers to determine their eligibility. Those found to be eligible and still desiring to participate were sent a letter outlining the details about the scheduled session. See **Attachment B** for a sample copy of this letter and attendant screening form.

Contacts were made with several Hispanic and Asian organizations to solicit their help in recruiting and developing language appropriate materials. These efforts failed to yield the inclusion of any participants in the focus groups. One Korean male responded to the notice of the proposed focus groups in the newspaper. However, his wife called Mr. Sanders to say that she did not feel that her husband's language skills were adequate to be a part of a discussion group. An African American male advocate, not diagnosed with prostate cancer, but with a number of relatives and who have prostate cancer, contacted Mr. Sanders, signed up his relatives and friends, and accompanied them to the focus group session. This individual's name was given to Mr. Sanders by a nationally recognized prostate cancer advocate who learned about the project.

Male individuals to serve as prospective facilitators were also identified in this phase of project development. Each individual was contacted and asked to submit a resume or curriculum vitae. Criteria for selection included previous training/experience as a facilitator and degree of availability. An effort was made to match the race/ethnicity of the facilitator with that of the prospective race/ethnic specific groups. After a review of their credentials, five candidates (i.e., Chinese, Korean, African American, Hispanic, and Caucasian)were invited to attend an informational meeting to outline the proposed

project, provide some background on the topic of prostate cancer, and discuss issues that could arise in the focus groups. These issues included such possibilities as when an individuals dominate the discussion, a participant's difficulty in talking about "God," or discussing problems related to sexual dysfunction. The candidates were also involved in recruiting efforts through their jobs and social/cultural networks.

Task 3 Conduct instrument development focus groups.

- a) A two-day meeting with Dr. Pargament in Bowling Green, OH took place on March 14 and 15. The meeting focused on the refinement of the focus group instrument and modifications of the proposed tasks for the remaining months of the training grant. Of particular importance, was the issue of how to incorporate some of the more sensitive topics such as sexual functioning and feelings of isolation often associated with a disease such as prostate cancer. Dr. Pargament's training and experience as both a clinical psychologist and researcher in the area of religion and coping suggested the use of vignettes that participants could review and respond to as a hypothetical case. Two very brief videos were developed. The first one depicts a newly diagnosed patient confronting feelings of loneliness and isolation and the second, a patient expressing concern over the future of his sexual capability to satisfy his spouse.
- b) The final draft of the interview guide was completed after review and input from the collaborative investigator, four prostate cancer advocates [who are also patients] and members of the study team. The final number of items in the interview guide were reduced to allow for adequate discussion in the focus groups, not to exceed two hours.

The supplemental quantitative survey included demographic information and additional items related to religious affiliation and attendance, spiritual beliefs, social support, symptoms, perceptions of causes of prostate cancer, knowledge of prostate cancer treatments, and quality of life and physical well-being. The "Beliefs About God Items"(In Zinnbauer & Pargament, 1997) scale was used to assess beliefs about God before and after the diagnosis of prostate cancer. See **Appendix 1** for a description of the scale. The survey items were designed to correspond with the focus group topics. See **Attachment C** for a copy of the spirituality survey and **Attachment D** for a copy of the focus group guide.

- c) A total of five focus groups was held between May 11 and June 23, 1999. It became apparent soon after the start of the grant that more planning time was needed to adequately recruit multi-racial/ethnic participants to assess sociocultural differences in spirituality and coping with prostate cancer. All participants were telephoned by Mr. Sanders prior to their scheduled meeting and were asked to arrive a few minutes early to sign consent forms (See **Attachment E**), receive a \$20 payment in appreciation of their contribution, have refreshments, and complete the survey. Mr. Sanders issued the surveys as participants arrived and offered assistance with questions. See **Tables 1** and **2** for the demographic characteristics of participants in the survey and focus groups. See

Appendix 2 for the qualitative analysis of the focus groups.

Nine men who were unable to participate in the focus groups completed the quantitative supplemental survey by mail and telephone. The key results of the survey relative to aspects of spirituality and quality of life are described in **Tables 3** through **8**.

- d) Following the first focus group the project team, including the facilitator, met for a debriefing session. Minor logistical modifications were made for the additional sessions. Two sessions with African American and White men at Andrews Air Force Base were held simultaneously. Unfortunately, the physical space provided for the sessions was not the most conducive and made some of the logistics more challenging to maneuver.

Ongoing project staff meetings were conducted including telephone conferences with the collaborative investigator throughout the period of the grant. Additionally, transcripts and recorder's notes were always available for review by the team.

Task 4 Conduct pretest focus groups.

- a) Another meeting was held with the collaborative investigator to review the progress of project activities. Dr. Pargament reviewed the transcripts and preliminary survey data and offered insights that are reflected in the analyses and discussions about the focus groups and the supplemental survey. He was not able to observe first hand any of the focus groups due to scheduling and time constraints. Nonetheless, Dr. Pargament remained involved throughout the project and was always accessible by electronic mail and telephone.
- b) The decision to include race/ethnic-specific focus groups was to determine if sociocultural differences existed in how patients acknowledged and utilized spirituality in coping with prostate cancer. The supplemental quantitative survey could not be considered as the final survey instrument because of the lack of inclusion of either Asians or Hispanics in the focus groups and being unable to perform psychometric evaluations. What emerged from the analyses of both the focus groups and supplemental surveys was a consistency in the responses between the two instruments but cross-cultural relevance could not be adequately assessed with the existing sample.
- c) The basis for not performing pretests of the final survey instrument was explained in item b).
- d) Psychometric testing of the supplemental survey was not performed for the reasons described in items b) and c).

Task 5 Prepare summary report

- a) A fourth meeting with the collaborative investigator was determined to not be needed.
- b) Focus group and supplemental survey findings were reviewed by each individual involved in the project. Input was contributed by project members and reflected in all final documents. The remaining items, c) and d), were encompassed in this task.

KEY RESEARCH ACCOMPLISHMENTS

Each of the accomplishments refers to the completion of tasks outlined in the approved Statement of Work.

- Implementation of qualitative and quantitative research methods that have begun to inform the understanding of the influence of spirituality in coping with prostate cancer in a small cohort of African American and Caucasian prostate cancer patients.
- Development of a preliminary quantitative instrument that may have application for use by health care providers in assessing quality of life factors such as spirituality, social support, sexual functioning, disease symptoms, physical well being, and other factors such as perceptions about causes of prostate cancer, knowledge about treatment options, and physician-patient interaction in prostate cancer patients.
- Formation of the basis for another research study with a significantly larger sample to test the psychometric properties of a prostate cancer quantitative instrument.
- Creation of a network of providers, advocates and patients focusing on issues related to prostate cancer for future collaborative efforts and research involvement.
- An opportunity to work with Dr. Kenneth Pargament, an established and well respected behavioral scientist and clinician in the field of religion and coping, and gain additional training and experience in becoming an independent researcher in the areas of prostate cancer, quality of life, and spirituality. His contribution to the study was extremely valuable in providing a conceptualization of the relationship of religious coping to serious threat such as prostate cancer.

REPORTABLE OUTCOMES

- Abstract submission and acceptance of highlights of the training grant research for roundtable presentation at the 1999 American Public Health Association Conference, Chicago, IL on November 11, 1999. See **Appendix 3** for a copy of the abstract and the acceptance notice.

- Presentation on the topic of religion and coping including discussion of the training grant research delivered by the collaborative investigator, Dr. Kenneth Pargament, the guest speaker for a noontime seminar on August 6, 1999 at the Johns Hopkins University School of Hygiene and Public Health, Department of Health Policy and Management.
- Radio interview on WEAA- FM morning talk show about the training grant research and focus group discussions.
- Inclusion of a brief article for Medcast, a medical internet access for physicians. See **Appendix 4** for a copy of this document.
- Development of a video of two brief vignettes for use in the focus group discussions. A copy of the video will be forwarded under a separate cover.
- Presentation delivered on the training grant research and collaboration with Dr. Kenneth Pargament to psychology students and faculty at Bowling Green State University, Bowling Green, OH on March 15, 1999. The presentation coincided with a visit with the collaborative investigator to confer on activities related to the research training grant.
- Presentations (promised but not yet scheduled) to be delivered to two prostate cancer support groups that had members in the focus group sessions.
- Agreement to provide a one-page summary highlighting the results of the training grant research to participants in the focus groups and respondents who completed the quantitative surveys.
- Invitation from the Dean and faculty of Haifa University School of Nursing, Haifa, Israel to discuss the training grant research findings as part of a scheduled visit there in February, 2000. The invitation arose out of collaboration and involvement of Dr. Michal Granot in the training grant research activities during her postdoctoral appointment with Hopkins.

CONCLUSIONS

- The qualitative research findings from the five focus group discussions provided some understanding of the role of spirituality in coping with prostate cancer. In the sample of patients, a majority of the men acknowledged a belief in God or a "higher power" and an affiliation with a place of worship. While most were post-treatment, these findings, along with others pertaining to symptoms, social support, and quality of life, may have varied had there been patients reflecting different stages of disease.
- Racial differences in spirituality were only distinctive in the conceptualization of religion/spirituality with African American men showing a trend towards a more intrinsic form of belief, suggestive of God being more integrated into their daily lives. Also, African American men expressed a stronger value of the need to share their experiences

with other men who have prostate cancer.

- The supplemental quantitative survey allowed for additional information to be collected from the focus group participants and nine other men who were unable to attend one of the sessions. The quantitative items and the data collected yield a strong correspondence with the focus group discussion and findings. Of particular relevance is that this draft instrument forms the basis for the refinement and performance of psychometric testing in a larger sample, leading to the development of a potential quantitative instrument that would assess the influence of spirituality in coping with prostate cancer.
- Both the focus group and the quantitative survey findings point to the need to further explore issues concerning doctor-patient communication, particularly as it relates to the issue of spirituality and the involvement of clergy in the treatment and care of patients with prostate cancer. This would be an important research consideration should funding become available to carry out the psychometric evaluation of the draft quantitative instrument.
- The demographics of the men who completed the quantitative surveys were not significantly different from those who participated in the focus groups and completed surveys, nor were there differences in responses. Also, we were concerned about a bias of issuing the survey before the focus groups but again, no significant differences were evident between the two groups. (Note: Given the similarities between the two groups, no analyses by participant type have been included).
- Although many strengths are associated with this training grant, a major limitation was a lack of adequate time to perform all the tasks outlined in the original proposal. Nonetheless, a great deal work was completed by many paid and non-paid faculty, students, and staff and we are proud of the results of the research.
- A cohesive group of knowledgeable and experienced researchers has been formed and are expected to continue as a committed body looking to future research opportunities to further the work begun through the training grant.
- This training grant opportunity enabled the recipient to establish a body of research that can lead to further examination of issues related to spirituality, prostate cancer and quality of life. Additionally, the training grant research is complimentary to the goals of another DOD funded prostate cancer grant examining the influence of religious teaching at a denominational level on prostate cancer screening in three African American church denominations.

LIST OF PERSONNEL RECEIVING PAY FROM THE RESEARCH EFFORT

Dr. Michal Granot, a one-year Postdoctoral student, expressed interest in working with Drs. Bowie and Pargament, and Mr. Sanders on this project. Dr. Granot is on faculty in the School of

Nursing, Haifa University, Haifa, Israel. Dr. Granot accompanied Dr. Bowie on the first visit to Bowling Green State University, Bowling Green, OH to meet with the collaborative investigator, Dr. Pargament. Monies from the training grant was used to cover Dr. Granot's travel expenses.

Kim Sydnor, a doctoral candidate, contributed her interest in spirituality and expertise in qualitative research to the project. Ms. Sydnor and Mr. Sanders were paid as research assistants (RA) as designated in the proposal. They were not paid simultaneously but at different times for different aspects of the project. All other paid project staff are listed in the original proposal.

SURVEY RESULT TABLES (Highlights of Findings)

Notes:

- (1) Numbers represent % with frequencies contained in the parentheses all tables except those noted as descriptive
- (2) n=14 blacks and n=25 whites unless otherwise indicated

Table 1: Demographics I - descriptive

	Black (n=14)			White (n=25)		
	Mean	SD	Range	Mean	SD	Range
Age	62.43	9.05	49-78	68.44	7.23	52-79
Yrs of education	13.00	1.47	12-16	15.00*	2.30	12-20
Yrs since diagnosis	5.07	2.59	1-12	6.46*	7.64	1-36

*n=24

Table 2: Demographics II

	Black	White
Marital Status		
<i>Married</i>	85.7 (12)	88.0 (22)
<i>Separated</i>	7.1 (1)	0.0 (0)
<i>Divorced</i>	0.0 (0)	4.0 (1)
<i>Widowed</i>	0.0 (0)	8.0 (2)
<i>Missing</i>	7.1 (1)	0.0 (0)
Work Status		
<i>Full time</i>	35.7 (5)	8.0 (2)
<i>Part time</i>	0.0 (0)	8.0 (2)
<i>Retired</i>	35.7 (5)	56.0 (14)
<i>Unemployed</i>	0.0 (0)	8.0 (2)
<i>Missing</i>	28.6 (4)	20.0 (5)

Table 3: Member of a church?

	Black	White
<i>Church member</i>	92.9 (13)	68.0 (17)
<i>Non-church member</i>	7.1 (1)	32.0 (8)
<i>Missing</i>	0.0 (0)	0.0 (0)

Table 4: Denomination

	Black	White
<i>Protestant</i>	71.4 (10)	28.0 (7)
<i>Catholic</i>	0.0 (0)	20.0 (5)
<i>Jewish</i>	0.0 (0)	20.0 (5)
<i>Other</i>	7.1 (1)	4.0 (1)
<i>Missing</i>	21.4 (3)	28.0 (7)

Table 5: Change in church attendance? (derived from 2 items)

	Black	White
<i>No change</i>	71.4 (10)	52.0 (13)
<i>Attend less</i>	7.1 (1)	16.0 (4)
<i>Attend more</i>	21.4 (3)	20.0 (5)
<i>Missing</i>	0.0 (0)	12.0 (3)

Table 6

	Did the doctor ask about your spirituality?		Did the doctor suggest spiritual material?		Did you tell your doctor about your religious beliefs...?	
	Black	White	Black	White	Black	White
<i>No</i>	50.0 (7)	100.0 (25)	64.3 (9)	68.0 (17)	35.7 (5)	84.0 (21)
<i>Yes</i>	42.9 (6)	0.0 (0)	21.4 (3)	32.0 (8)	64.3 (9)	12.0 (3)
<i>Missing</i>	7.1 (1)	0.0 (0)	14.3 (2)	0.0 (0)	0.0 (0)	4.0 (1)

Table 7: Have your doctor and clergy been in contact/would you want them to? (derived from 2 items)

	Black	White
<i>Concordant pairs*</i>	57.1 (8)	56.0 (14)
<i>Did not/did want mtg</i>	28.6 (4)	12.0 (3)
<i>Did/did not want mtg</i>	7.1 (1)	16.0 (4)
<i>Missing</i>	7.1 (1)	16.0 (4)

* the majority of the concordant pairs were instances where clergy and doctor did not meet

Table 8: Scale Items - descriptive

scales of 1 - 10 with 1 = not at all; 10= 0 very much ...

	Black (n=14)			White (n=25)		
	Mean	SD	Range	Mean	SD	Range
Worry about cancer spreading/returning	3.54*	2.88	1-10	3.82	2.66	1-10
Importance of physical health	5.64	3.59	1-10	5.80	3.91	1-10
Quality of life before cancer	9.59	.85	8-10	8.96	1.72	4-10
Quality of spiritual life post-cancer	9.21	1.31	6-10	8.29**	2.56	1-10
Recovery depend on spirituality	8.86	2.51	1-10	6.96	3.59	1-10

*n=13

** n=24

ATTACHMENT A

Men With Prostate Cancer

Needed to take part in group discussions

Meet to talk about the role of religion and spirituality
in the experience of prostate cancer.

To take part in this public health study you should....

- Have been diagnosed with prostate cancer
- Be 50-75 years of age
- Identify with one of four racial/ethnic groups:
African-American, Asian, Hispanic/Latino, or White/Caucasian
- Be English Speaking
- Be able to come to one evening focus group

Takes approximately 2 hours

You will receive \$20.00 for participation

Refreshments will be provided

Interested?

Call Mr. Bruce Sanders at (410)955-2315



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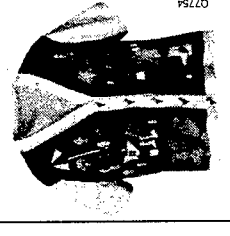


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RPN: AAC98-12-10-01

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ATTACHMENT B

School of Hygiene and Public Health

Department of Health Policy and Management
Faculty of Social and Behavioral Sciences
624 N. Broadway, 7th Floor
Baltimore MD 21205-1996
(410) 955-2312 / FAX (410) 955-7241

Dear Mr.

Thank you for expressing interest in the prostate cancer study. We plan to hold several discussion groups to talk with men who are between the ages of 50 and 75 and have been diagnosed by a physician as having prostate cancer.

The purpose of the discussion is to create a survey to learn how men use their spiritual beliefs to cope with the disease. We are performing the study so that we can help them better deal with prostate cancer. Each discussion group will include men who are close in age and of the same race or ethnic group as you. The discussion will be led by a man and will last for two hours. You will be paid \$20 cash at the end of the session for your help.

Everything that is talked about will be kept in private. We are only interested in information that is discussed as a group, not you the individual. The discussion group will be tape recorded so that we do not have to write down answers to every question. After the discussion group is finished, nothing about you as an individual person will be identified. The tapes will be typed, coded by an identification number, and then erased.

If you decide to participate in the discussion group, Mr. Bruce Sanders from the study team will call you at the telephone number(s) you provided to us. Please complete the enclosed form included with this letter if you decide to participate. We have included a self-addressed stamped envelope to make it easier for you to mail it back within one week. Be sure to tell us the best times to reach you. If you do not want to participate in the discussion group, you can tell us that and we will not try to contact you again.

Dr. Janice Bowie at the Johns Hopkins University School of Hygiene and Public Health is leading the study. Please feel free to call her at 410-614-6119, or Mr. Bruce Sanders, who is working with Dr. Bowie, at 410-955-2315. We hope that you will agree to be part of this important study on prostate cancer. Thank you.

Sincerely yours,

Janice V. Bowie, Ph.D.
Assistant Professor

cc: Mr. Bruce Sanders
Enclosures

SCREENING FORM FOR PROSTATE CANCER FOCUS GROUPS

NAME: _____

ADDRESS: _____

PHONE NOS. (Home) _____ (Work) _____

(Fax) _____ EMAIL ADDRESS: _____

AGE _____ YEARS OF SCHOOL _____

MARITAL STATUS:

____ Married ____ Single ____ Divorced ____ Separated ____ Widowed ____ Partnered

EMPLOYMENT STATUS:

____ Working full-time ____ Working part-time ____ Retired

____ Disabled (If yes) Please describe: _____

RACE/ETHNICITY

____ Black ____ Asian ____ Latino ____ White

Estimated of diagnosis for Prostate Cancer _____

Are you receiving any prostate cancer treatment now? _____

(If yes) What kind? _____

PREFERRED TIMES TO ATTEND

____ Weekdays Which ones? _____

____ Evenings, during week

____ Saturdays Other _____

How did you learn about this study? _____

NOTES: _____

ATTACHMENT C

Prostate Cancer and Spirituality Survey

I. Attendance

1. Are you now a member of a particular church or religious group?

☐ Yes.

☐ No. If no please skip to question 3.

2. Which denomination do you belong to now? _____

For how many years? _____

3. Before your prostate cancer, how often did you attend church or a place of worship (other than funerals and weddings)?

☐ Weekly or more often

☐ 2-3 times per month

☐ Once per month

☐ Other (please specify) _____

4. Did your attendance change after your disease?

☐ No. If no Please skip to question 5 in the next page

☐ Yes. If yes, Please describe in what manner:

☐ **Attended less often.** Please check all the reasons that apply.

☐ Lost interest

☐ Not able physically

☐ Don't want to be around others at church

☐ Other reasons (please specify) _____

☐ **Attended more often.** Please check all the reasons that apply.

☐ Enjoy the services

☐ Gain more spiritual support

☐ Need the fellowship

☐ Insistence from spouse or family member

☐ Other reasons (please specify) _____

☐ **Attended stayed the same**

II. Diagnosis and treatment

5. What treatment are you receiving now? Please check all the answers that apply.

- ☐ Chemotherapy
☐ Radiation
☐ Hormonal
☐ Other
☐ None

6. Is there a history of prostate cancer in your family?

- ☐ Yes
☐ No
☐ Don't know

7. Please check the type of belief in God that best fit you **before diagnosis and now**.

Before diagnosis	Now	
		I believe that God is all around us. I look to nature to see God. I see God in every person I meet. I believe God is involved in everything we do and touches every person.
		I believe God is a personal being who reigns over all creation, who looks after us and listens to our prayers and praise. He responds to our needs and protects us from evil.
		I believe God created the world and everything in it and then left us to fend for ourselves. God is no longer involved in the happenings of this world and looks down on us from above without ever intervening in our lives.
		I am not sure what or who God is but I do think that it is beyond our understanding to comprehend such ultimate things. I often wonder if there is a God, but I do not think that I will ever know for sure.
		I do not believe that there is a God. I do not believe that God created the world or controls our affairs. There is no higher power that can intervene in our lives.

8. At the time of diagnosis, were you familiar with or aware of the common procedures associated with prostate cancer screening, treatment, and prognosis? (Such as PSA blood test, rectal examination, prostate surgery, radiation, chemotherapy). Please circle yes or no.

PSA blood test	Rectal examination	Prostate Surgery	Radiation	Chemotherapy
Yes	Yes	Yes	Yes	Yes
No	No	No	No	No

9. A number of factors have been thought by some men to cause prostate cancer. Do you agree with any of these? Please mark your choice.

	Agree	Do not agree	Do not have an opinion
Eating fatty foods			
Drinking too much alcohol			
Smoking			
Exposure to the air during an operation			
Lack of regular exercise			
Viral infection or bacteria			
Genetics			
Worrying or stress			
Having sex with different partners			
Having sex without wearing a condom			
Masturbating			
God teaching a lesson			
Devil or satan			
No known cause discovered yet			

10. Estimated date of your prostate cancer diagnosis _____

11. How were you diagnosed?

___ During a routine check up

___ Experienced symptoms

___ Other, please specify _____

12. At the time of diagnosis, was there any person(s) who helped you get through the experience? If yes, who was this person(s)?

___ Spouse/partner

___ Brother

___ Friend

___ Co-worker

___ Other, please specify _____

___ No one

13. What kind of help was offered? Please check all that apply.

- ☐ Provided you a shoulder to lean on
- ☐ Enabled you to express how frightened or angry you felt
- ☐ Accepted you as you were
- ☐ Gave you a feeling that he/she understood what you were going through
- ☐ Other, please specify _____

14. If no, who do you think would be the **most** helpful?

- ☐ Spouse/partner
- ☐ Another male with prostate cancer
- ☐ Friend
- ☐ Other, please specify _____

15. What, if any, symptoms are you having now? Please check all that apply.

- ☐ Pain
- ☐ Nausea
- ☐ Vomiting
- ☐ Urine problems
- ☐ None
- ☐ Other, please specify _____

16. Are you forced to spend time in bed?

- ☐ No
- ☐ Yes. If yes, how much time do you spend in bed other than for night time sleeping?
 - ☐ 30 minutes
 - ☐ 1 hour
 - ☐ 2 hours
 - ☐ 3 hours
 - ☐ More than 3 hours
 - ☐ Other, please specify _____

17. Does anyone in your church or place of worship know about your disease?

- ☐ Yes
- ☐ No, please skip to question 22

18. In what way has the church assisted you since the diagnosis?

☐ Provided food

☐ Provided transportation

☐ Provided money

☐ Came to visit

☐ Prayed

☐ Other, please specify _____

☐ Church did not assist

19. Does it matter to you that they have knowledge of your disease?

☐ Yes

☐ No

20. Has your doctor ever asked you about your spirituality or religion as part of helping you to handle the disease?

☐ Yes

☐ No

21. Have you told your doctor anything about your sense of spirituality or religion?

☐ Yes

☐ No

22. Has your doctor suggested any of the following? Please check all the answers that apply.

☐ Scriptures to read

☐ Daily devotional reading

☐ Bible reading

☐ Prayers

☐ Meditation

☐ None

23. Have your doctor and clergy been in contact with each other since your diagnosis?

☐ Yes

☐ No

24. Would you want your doctor and clergy to be in contact with each other?

☐ Yes

☐ No

☐ Other. Please describe: _____

25. Rate on a scale of 1-10 how **worried** are you about your cancer returning or spreading?

1	2	3	4	5	6	7	8	9	10
Not at all									Very
Worried									Worried

26. How much does your current **physical well-being** affect your quality of life, i.e. how well you feel and function?

1	2	3	4	5	6	7	8	9	10
Not									Very
at all									much

27. What was your **quality of life** like before your diagnosis of prostate cancer?

1	2	3	4	5	6	7	8	9	10
Very									Very
poor									good

28. What is the quality of your **spiritual life** like now or since your diagnosis of prostate cancer?

1	2	3	4	5	6	7	8	9	10
Very									Very
poor									good

29. How much does your **recovery from prostate cancer** depend on your spirituality or relationship with God or a "higher power"?

1	2	3	4	5	6	7	8	9	10
Does not									Depends
depend									very
at all									much

ATTACHMENT D

Prostate Spirituality Instrument Development Focus Group Guide

*** Introduction:**

My name is...

Aim of our meeting is to talk about spirituality. We are interested in your feelings about God or a "higher power" and yourself. This does not necessarily have to do with whether you belong to a particular denomination or attend a church or place of worship.

The process we will follow is to spend a few minutes asking you to complete a survey. Then, the remaining time we will spend discussing issues relating to prostate cancer and spirituality.

***Facilitators you may feel free to design your own introduction.**

Effect of prostate cancer on life in general

1. How has your disease affected the things that matter to your life? Has having prostate cancer changed your life and the things you were striving for? (Probe: Things that you care about, priorities, things that you are striving for).
2. Some men reported a change in church or place of worship attendance since their diagnosis of prostate cancer. Is this experience at all familiar to some of you? Why do you think this happens?
3. Would you want your church or place of worship to be involved in your experience of prostate cancer? If so, how might they offer help to you?
4. Do you see doctors as instruments of God? (Probe - Do you perceive your doctors as having been sent by God to treat and care for your disease)?

Videotape Vignette no. 1

I used to have a very personal intimate relationship with God. I thought everything I did and every move I made God knew and was right there.... He'd be there for me, watching over me. Then I get news that I have prostate cancer and where did He go? Why is this happening to me? God was no longer near me. Disappeared. And I am no longer the person I used to be.

- What are your thoughts about this?
 - Follow-up questions:
 - Do you think that the way he feels is unusual?
 - Do you have any ideas of how he could better cope with these feelings?
 - Are there any spiritual explanations that you can offer him?
 - In your opinion, will his faith in God ever be restored? Why ?
 - In what ways might the church or place of worship be helpful
5. Do you wonder sometimes whether God has abandoned you in the midst of your disease?
 6. Do you ever question whether God really exists? (When? At what time does this question occur?)
 7. How do you see God? What kind of relationship do you have with God?
 8. How do you understand why you got prostate cancer from your religious point of view? (Probe: Do you think that getting prostate cancer was part of God's will? Why?)
 9. What are your biggest worries about your disease?
 10. Has your sense of spirituality played any role in helping you understand or read with your own prostate cancer? (Probe: In what ways?)
 11. Has your sense of spirituality been less than helpful or even harmful? (Probe: In what ways has your spirituality been a burden to you in dealing with having prostate cancer?)
 12. Where do you think the best things in your life have come from? Where do you think the worse things in your life have come from?

Effect of prostate cancer on intimate relationships and sexual life

Videotape Vignette no. 2:

This is so embarrassing.... How can I still be a man? I am afraid that I am not going to be able to satisfy my wife and she can't possibly understand what I am going through. I can't talk to her or anyone else about this. I feel so alone. What am I going to do... How will I survive this?

- What are your thoughts about this? How do you feel about this?

- Follow-up questions
 - What would you say to him?
 - Do you have any ideas of how he could better cope with these feeling?
 - Are there any spiritual explanations that you can offer him?
 - Do you think that the place of worship could be helpful to him? Why?
- Additional follow-up questions about this issue but only ask if necessary.
 - How does a person's trust in God affect whether or not one feels shame, guilt, embarrassment, difficulty in his intimate relationship with his wife or partner?
 - What kind of spiritual support do you think would be helpful (For example: If pastoral counseling would be helpful, what should be the focus of the encounter? Should the counselor help the men to find ways to feel less shame, and guilt and to talk about their feelings?)

Many prostate cancer patients express difficulties in their intimate relationships.

- Why do you think this happens?
- Who can help address these problems?
- Do you think that your faith or spirituality is affected by your wife's spirituality, or her relationship with God? In what ways do you benefit or feel burdened from this? (For example: Does she pray for you, get you to go to church, pray with you, get you to read the Bible, or encourage you to talk to family or friends?)

ATTACHMENT E

JAN 2

The Johns Hopkins University
School of Hygiene and Public Health
Committee on Human Research

CONSENT FORM A

Title of Research Project:

CHR#H.30.98.11.04.A

Assessment of Spirituality as a Function of Quality of
Life in Prostate Cancer Patients

Explanation of Research Project:

STUDY TEAM: This study is being paid for by the U.S. Army Medical Research and Materiel Command and led by Dr. Janice Bowie, Johns Hopkins School of Hygiene and Public Health and Dr. Kenneth Pargament, Bowling Green State University.

PURPOSE OF STUDY: As part of a research study on prostate cancer, we are holding eight discussion groups with men to talk about prostate cancer. The purpose of the study is to create a survey that will help us understand how men use their faith to cope with prostate cancer. We have contacted you for this study because you showed interest in talking with us about prostate cancer.

PROCEDURES: If you decide to participate in the discussion group, we will talk with you and four to seven other men for about two hours. We will ask you about symptoms, when you were told that you had prostate cancer, type of medical care, and what your life has been like since having prostate cancer.

RISKS/DISCOMFORTS: Please let us know if there are any questions or parts of the discussion that make you feel uncomfortable or troubled. You do not have to answer any questions that you do not wish to and you may excuse yourself from the group at any time.

BENEFITS: We hope that in talking with you and others that we can find out how to help men deal with prostate cancer and how their faith may affect how they feel about the disease. You will receive a payment of \$20 for your time and help with this study.

PRIVACY: Everything that is talked about in the discussion group will be kept in private. We will keep all files in a locked cabinet in Dr. Bowie's office. We are only interested in information that is discussed as a group, not you the individual. The discussion group will be tape recorded so that we do not have to write down answers to every question. After the discussion group is finished, nothing about you as an individual person will be identified. The tapes will be typed, coded by an identification number, and then erased.

THIS CONSENT FORM CONTINUES ON THE REVERSE SIDE

(CHR New Application Form/Rev. 7/97)

Side Two:
(Consent Form A/New Research Project)

You should ask the person in charge listed below any questions you may have about this research study. You should ask him/her questions in the future if you do not understand something about the study. The researchers will tell you anything new they learn that they think will affect you.

If you want to talk to anyone about this research study you should call the person in charge, Janice V. Bowie, Ph.D. at (410)614-6119, or call the Office for Research Subjects at (410)614-1856/FAX (410)955-0258. The person in charge of the study or the people in the Office for Research Subjects will answer your questions and/or help you to find medical care if you are hurt during the study.

If you agree to be in this study, please sign your name below.

Subject's signature

Witness to Consent Procedures*

Signature of Investigator

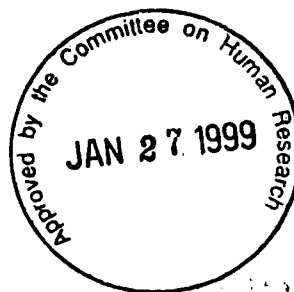
Date

*Optional unless subject is illiterate, or unable to sign.

Note: Signed copies of this consent form must be a) retained on file by the Principal Investigator, b) given to the participant, and c) put in the patient's medical records (when applicable).

(CHR New Application Form/Rev. 7/97)

NOT VALID WITHOUT THE
COMMITTEE OR IRB STAMP OF
CERTIFICATION



CHR No.

H. 30.98.11.04. A

1/06/2000

APPENDIX 1

BELIEFS ABOUT GOD ITEMS

- Pantheistic:* "I believe that God is all around us. I look to nature to see God. I see God in every person I meet, I believe God is involved in everything we do and touches every person."
- Theistic:* "I believe God is a personal being who reigns over all creation, who looks after us and listens to our prayers and praise. He responds to our needs and protects us from evil."
- Deistic:* "I believe God created the world and everything in it and then left us to fend for ourselves. God is no longer involved in the happenings of this world and looks down on us from above without ever intervening in our lives."
- Agnostic:* "I am not sure what or who God is but I do think that it is beyond our understanding to comprehend such ultimate things. I often wonder if there is a God but I do not think that I will ever know for sure."
- Atheistic:* "I do not believe there is a God. I do not believe that God created the world or controls our affairs. There is no higher power that can intervene in our lives."

Zinnbauer, B.J., Pargament, K.I., Cole, B., Rye, M.S., Butter, E.M., Belavich, T.G., Hipp, K.M., Scott, A.B., and Kadar, J.L. 1997. "Religion and Spirituality: Unfuzzifying the Fuzzy." Journal for the Scientific Study of Religion 36(4):549-564.

APPENDIX 2

Assessment of Spirituality as a Function of Quality of Life in Prostate Cancer Patients

Focus Group Qualitative Analysis

Part 1: Setting

Focus groups were held as a part of the Spirituality Study among men diagnosed with prostate cancer. Five sessions took place between the time of May 11 - June 23, 1999. Three different settings and three facilitators were utilized in conducting the group session. The groups were constructed as follows:

Session #	Date	Location *	# in Group	Ethnic Mix	Facilitator
1	5/11/99	JHSPH	8	white males	white
2	5/17/99	AAFB	7	white males	Hispanic
3	5/17/99	AAFB	4	black males	Af-American
4	5/24/99	JHSPH	7	black males	Af-American
5	6/23/99	JHSPH Greenspring	4	black/white	Hispanic

* JHSPH = Johns Hopkins University School of Hygiene and Public Health; AAFB = Andrews Air Force Base; Greenspring = Johns Hopkins facility located in Greenspring, MD

Note: The Andrews Air Force Base men belong to a prostate support group in LaPlata, Maryland.

Each facilitator guided the discussion based on a prepared set of probes. A sample of the questions include:

- (1) *Do you see your doctors as instruments of God?;*
- (2) *Has your sense of spirituality played any role in helping you understand your own prostate cancer?;* and
- (3) *Do you wonder sometimes whether God has abandoned you in the midst of your disease?*

Additionally, the focus group participants were presented two videos containing vignettes with male actors discussing two issues relevant to prostate cancer which could be entitled "Why me?" and "What about my sexuality?" The video tapes were used to help direct and generate discussion around these two key issues.

Sessions were audio taped as well as recorded by an observer. The data used for the qualitative analysis were generated from the transcriptions of the audiotapes and the observer notes. In one setting (Session #1) the audiotape was inaudible and consequently the observer notes were relied upon for analysis. In Session 3 the tape malfunctioned half way through the session and so the observer notes were relied upon for the final portion of the focus group discussion.

Part 2: Results

Group Summary

Below is a brief summary of each of the sessions. These observations reflect dynamics that seemed to be unique to the particular focus group.

Session I:

There was a general sense that the men in the group were not currently worried about their cancer. This could reflect their stage of the disease, most being post-treatment. Most of the men felt that doctors were not open to discussing emotional and spiritual issues with them, though quite a few felt that this was an important aspect of treatment. The discussion relative to sexual issues was limited in comparison to issues of spirituality, social support, and treatment options. This may reflect the generally older age of these men. The discussions around religion and spirituality were broad. This may reflect the fact that at least 2 of the men did not express a belief in God as a presence in their lives.

Session II:

There was much more discussion around issues of sex in this group. The men discussed the stigma attached to prostate cancer and fears of sexual dysfunction. The age group of these men is somewhat younger than the first group. Most of the men (5 of 7) expressed a belief in God, with one of these men indicating no institutional affiliation but still having a belief. As well, this group of men seemed to have undergone a perspective shift in that they appreciate the immediacy of life post-diagnosis to a greater degree than before the diagnosis, i.e. "smelling the roses" mentality.

Session III:

There was considerable discussion around the importance of getting the word out among other men, black men in particular, relative to prostate cancer screening. Some of the men stated that they had become spokespersons about prostate cancer in their churches and places of work. This does not indicate that information dissemination was not an issue brought up at the other sessions, but that it appeared to be an ongoing matter of concern throughout the discussion in these two groups. This group was unusual in that there was an individual who was recently diagnosed with prostate cancer. His comments would seem to indicate that he had not yet integrated all the information and emotions surrounding the disease. One among the four in the group stated that he did not believe in God, though other statements seemed to contradict this position. The discussion was very centered around God, the church, and the Bible.

Session IV:

This group was similar in many aspects to group three in terms of expressing the need to advocate for cancer screening and the level and prevalence of the discussion around God and religion. All the men in the group expressed a belief in God.

Session V:

All of the men in this group indicated that their wives were the best thing that had happened to them throughout the disease process. Two men expressed belief in God; one man

seemed skeptical and the other indicated he had no belief in a higher power. In contrast with the other groups, three men saw the vignette actor's questioning of God as an unusual response and questioned whether or not the person portrayed ever had any real faith at all. This appeared to be the group with the least amount of consensus around the topic areas discussed.

Common Themes

In analyzing the five group sessions as a collective, there were quite a few common responses and themes present which really characterize the most important aspects of the focus groups:

(1) The need to tell their story

In each of the five sessions, there seemed to be a need for one or more individuals to tell of their personal experiences with prostate cancer, particularly around the issue of their diagnosis and treatment. In responding, at least one man in each group provided detailed information on the circumstances surrounding treatment and diagnosis.

Example:

How has prostate cancer affected those things that matter to you, that you're striving for?

When it was diagnosed on a routine physical because I had lost 65 lbs, my PSA went from 230 down to 160, and my wife, who is a doctor and my son who is also a doctor insisted I get a physical. The physical showed the PSA at 32. The normal PSA was 0 - 4. Inside of two months time the PSA had jumped from 35 to 65 so the surgeon told me not to procrastinate. He told me that I would have expired in September of '93. What I also witnessed was a younger brother die of prostate cancer recently. We buried him July of last year. He went from 170 pounds to about 85 pounds. I have seen close to 40 different guys that I have talked with and counseled expire. Many because they would not have surgery. Important to act quickly. To decide about treatment options....

(Note: Confidential information not for repeating or publishing.)

(2) Importance of wife/family and other support

A very common thread running throughout the sessions was the importance of wives, children, and other means of support in dealing with prostate cancer. The vast majority of the men indicated that the support of their wives was very helpful in dealing with prostate cancer, especially in helping them come to terms with changes in sexual functioning. Most men expressed fears and concerns early on within the disease process but reported that open communication with their mates helped them to cope with the sexual changes the prostate cancer had generated.

(3) Importance of religion and spirituality

The majority of men in the groups (n=22/32) expressed a belief in God as being a fundamental part of their lives and a resource for coping with prostate cancer. These men either pointed to their Christian faith or the value in collective Christian fellowship as being central to their finding a way to come to terms with their disease. Of these men, none expressed any prolonged periods of doubt regarding God's presence in their lives. For those who indicated a

change in their faith since diagnosis, the majority noted that their religious belief and/or practices had increased. About five men in all of the sessions indicated they were either non-believers or agnostic, i.e. acknowledging the possibility of the presence of a higher power but not placing any value on that power in their lives. Those expressing this view generally seemed to be aesthetics, i.e., appreciating the beauty to be found in life. There were five other men for whom a position on religion and spirituality could not be established based on their contributions to the discussion.

While many were believers, most did not believe that doctors needed to be spiritual nor were they instruments of God. There were two who felt that they would prefer doctors to have religious beliefs consistent with their own, but they were concerned about the doctor's competency to successfully treat the cancer. Many expressed the opinion that God was present whether the doctor believed or not, and therefore the issue of the doctor's spirituality was not that relevant.

Part 3: Summary Notes

In analyzing the data from the focus group sessions it would appear that religion and spirituality are a common method for coping with the uncertainty and anxiety produced by a diagnosis of prostate cancer. The role and centrality of religion do seem to differ by ethnic group. The analysis suggests that among these men, blacks tended to conceptualize religion in a more intrinsic fashion. Their discussion appears to place God in a more central and integral part of daily living. This is evidenced in the greater prevalence of Biblical reference and the discussion of the church and its teachings as pivotal to daily life. In contrast, the white males tended to discuss God in more general terms and, while very important in their lives, the discussion seemed not to be completely bound in a religious context.

What also stands out is the importance of the wives and other social support in dealing with prostate cancer. The wives seemed to be important from multiple standpoints: (1) as critical partners around the issue of sex and allaying those concerns; (2) as partners in faith and belief or even as a source of emotional comfort for those who stated no expressed non-belief; and (3) as instrumental support in handling issues around medical issues. Most of the men reported the value of sharing experiences with other men with prostate cancer as well as advocating for prostate screening among males in general. This need seemed to be most pressing among black males.

The third and final point to be made is that individuals seem to have the desire, under these conditions, to talk about their personal experiences relative to their cancer. It is likely that the need for "story telling" and the nature of the story is related to the individual's stage of the disease process.

Part 4: Strengths and Limitations

Strengths

The purpose of the focus groups was to aid in the development of appropriate instruments to investigate the role of spirituality and prostate cancer. To this end, the focus groups with a qualitative analysis were an excellent way to help generate the breadth and depth of questions that

would help in investigating the topic at hand. Unlike a structured interview instrument or a survey, the participants were free to expand upon their responses and carry the discussion into areas that may not have been anticipated.

Limitations

While there is depth and richness in the information gathered, the findings of the study are not generalizable due to the non-random sampling in the subject recruitment process and the small sample size. Most of the men have already undergone treatment and thus their perspective may differ significantly from persons newly diagnosed, as indicated in Session #4, or who have not yet been screened. The attitudes toward spirituality and the ties to spouses might vary greatly among the other groups noted.

In addition, two of the sessions were analyzed using only observer notes or observer notes and portions of tape transcriptions. Observer bias is always a possibility and other observations that might have changed the interpretation of the group dynamic may have gone unnoted for a variety of reasons.

APPENDIX 3



American Public Health Association

May 17, 1999

Dear Annual Meeting Presenter:

We are very please to inform you that your abstract has been accepted for presentation at the American Public Health Association 127th Annual Meeting to be held in Chicago, IL, November 7-11, 1999. Below please find the title of your accepted paper, the tentative day and start time of your presentation and the format (oral, roundtable or poster). You will received a mailing in July giving the location of your presentation. Please note the Preliminary Program will be a supplement to the July issue of The Nation's Health.

It is APHA policy that anyone presenting an abstract at the Annual Meeting must be an APHA member in good standing through November 1999. We also require that you register for the Annual Meeting. The necessary forms will appear in the July issue of TNH.

Abstract title: The Assessment of Spirituality as a Function of Quality of Life in Prostate Cancer Patients

Date: Thursday, November 11, 1999

Start time: 8:30:00 AM

Format: Roundtable Presentation

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Documentation of the link between spirituality and health and medicine is increasing. Studies continue to show that strength and comfort from religion and spirituality is a strong predictor of the rate of recovery, survivorship and quality of life (QOL). However, there is evidence that spirituality as a domain of QOL is sorely lacking, and that males and minorities are consistently not enrolled in cancer clinical trials. Clearly, there is a need to rethink ways of examining the contribution of spirituality to health outcomes in these underrepresented populations. The study is being carried out in two phases. **Objectives.** The specific aim of Phase I is to conduct qualitative data collection using race-specific focus groups to elicit beliefs about religion and spirituality in the lives of prostate cancer patients. The specific aims of Phase II are to (1) design a survey instrument using information collected from the focus groups to assess the role of spirituality as a measure of quality of life; and (2) pretest the instrument in a second set of race-specific focus groups. **Methods.** African American, Asian, Caucasian and Latino or Hispanic men between the ages of 50 and 75 are being recruited to participate in focus group discussions. **Results.** Completion of Phase I activities will lead to the development of relevant items for the survey instrument and in Phase II, psychometric evaluations will lead to the development of a valid and reliable survey instrument. The information gained could increase the understanding of barriers to timely diagnosis, optimal treatment and survivorship.

APPENDIX 4

Religion May Play a Role in the Diagnosis and Treatment of Prostate Cancer Patients

By Karen Infeld
Acting Medcast Bureau Chief
Johns Hopkins School of Medicine

The volume of literature on cancer and quality of life has grown since the mid-1980s, yet males, especially minorities, tend to be omitted from such studies. Minorities also have higher prostate cancer rates, are diagnosed at later stages of disease, have worse five-year survival rates, are less likely to be enrolled in clinical trials and have fewer support services readily available.

The combination of clinical and life quality research defects have led researchers at Johns Hopkins to explore religion's influence on prostate cancer diagnosis, treatment and quality of life.

"Religion and spirituality are significant personal and cultural resources within many racial and ethnic traditions and, therefore, offer a context for promoting health and well-being," says Janice V. Bowie, PhD., MPH., principal investigator for the study.

"Although cancer investigators sporadically have considered religion and spirituality as factors influencing cancer behaviors," she continues, "the research has suffered. Some physicians tend to reduce the concepts of religion and spirituality to stereotypes; others suggest that religion is a passive defense mechanism, precluding the possibility of a proactive component. Its value as a source of motivation and strength could be overlooked."

Funded by the Department of Defense, the Hopkins study will recruit prostate cancer patients aged 50 to 75 in four race-specific groups: African-American, Asian, Caucasian, and Latino/Hispanic.

All subjects initially will be assigned to focus groups by ethnicity to assess cultural factors that may be specific to only one group. Moderated by males of the same ethnicity, the groups will compare the men's religious beliefs before and after diagnosis, analyzing experience with the disease, the role of their place of worship in coping and how they perceive health care providers.

There are occasions, Bowie says, where spirituality influences the patient's treatment and lifestyle decisions, sometimes clashing with modern medicine rather than augmenting it. Results of the study are expected to help shape a questionnaire that health care professionals

could use to assess the role of spirituality as a measure of quality of life in their patients. The information gained also could increase understanding of barriers to timely diagnosis, optimal treatment and survivorship.

"Even before the results are compiled, health professionals should factor in a patient's religion when designing a treatment plan," Bowie says. "Asking the questions and, when necessary, involving the clergy, may profit patients' treatment and recovery."

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REPLY TO
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21 JUN 2001

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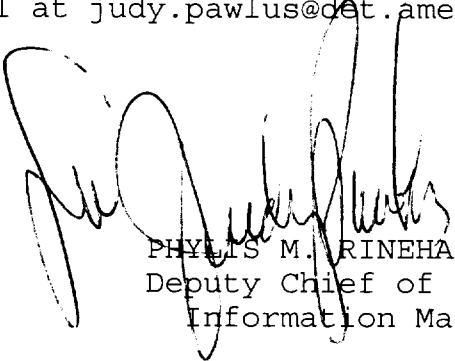
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